

Public Health Data Standards Consortium
WRC – Lewin Kick-off Conference call
September 27, 2002 11:00 – 12:30 ET

Lewin Staff:

Christina Worrall – Project Director
Jed Perry
Marihelen (Midge) Barrett
Debjani Bhaumik

Social & Scientific Systems Staff:

Alan Kendall – Project Director at SSS
Natalie Fike – Web Designer

WRC Workgroup Members:

Tom Doremus, Information and Communications Specialist
Public Health Foundation (PHF)

Bob Kambic, Professor of Health Informatics
Johns Hopkins University School of Health

Jeffrey Walter, Director, Information Services and Knowledge Management
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Vivian Auld, Senior Specialist for Health Data Standards
National Library of Medicine

Marjorie Greenberg, Chief
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National Center for Health Statistics (NCHS)

Suzie Burke-Bebbee, Health Informatics Specialist
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Tim Stephens, Director Education and Training
National Association for Public Health Statistics and Information Systems

Sally Klein, MT HIPAA Project Manager
National Association of State Medicaid Directors

Introduction

Christina Worrall introduced herself as the project director, and as someone who originally worked on the education system a few years ago. The Lewin group is currently working with Social and Scientific

Systems to create the web site. This call presents an opportunity to hear the vision for this effort. Lewin wants to get a sense of each product and what WG members want to accomplish with each product as well as establish some logistics. Recognizing that committee members are busy, every effort will be made to use time efficiently on the calls and accomplish some other things electronically.

Christina introduced the team at Lewin. Christina is being advised by Midge Barrett at Lewin. In addition, Jed Perry and Debjani Bhaumik at Lewin manage the daily work. Alan Kendall, director at SSS will be directing the web component. Natalie is the web designer to create the nuts and bolts of putting this up.

Discuss the overall vision for the Web site (substance and function)

Lewin and SSS wanted to hear from the WRC WG its vision for web site – specific to becoming a resource center for standards. They wanted to know where we see this moving forward and how it should relate to the NCHS, PHDSC, and NAHDO websites. Tom, as former chair of the WRC, indicated some of the workgroup ideas: 1) it should be a stand alone site, but reference NCHS, the Consortium, and NAHDO; 2) there should be links from NCHS for the annotated bibliography and it should also reside on the new site; 3) the site should maximize the search engine capacity; and 4) allow people to learn about health data research and standards. Essentially, everything in the contracts and white paper will be very important for the first generation of the site.

Suzie indicated that she wants to be sure that the web site remains educationally focused, as this has been the thrust of the Consortium. Although the first generation products are basically the shell of the web site, the content will be provided by the WRC members and the NAHDO contract. She also wants to be sure that the site is user friendly and very easy to maneuver.

Bob commented directly on the content of the educational components. A text only based tutorial could be rather boring. He believes that the public is used to looking at TV and therefore it would make sense to make this tutorial a series of 10 minute presentations done with streaming media as well as power point presentations. An audio tutorial could use someone who was very passionate about how standards enable new data and new ways to use it. Too many things should not be addressed in the same lecture.

Marjorie commented that there are many groups establishing web sites and talking about standards. The WRC does not want to duplicate these other sites, but leverage the educational materials that are available. The goal is to have people in public health go first to the WRC to understand the importance of standards to their work and learn how to access those standards using tools that are available. This site should be useful to local health department staff who don't have a lot of time or technical staff. Not everything needs to be created by us, but we should be a bridge to all of these other sites. Visitors to the site should also get help in navigating and interfacing with the processes that get standards changed to what they need. The site should be relevant to health services researchers who also need the standards to accomplish their goals.

Several other content and technical ideas were expressed. While connecting to other URLs, the visitor should be able to return to the Consortium when finished, and not be clicked away for good. There should also be user-friendly printing, which formats properly to the page. Users should be tracked and tallied to help plan the evolution of the site. The site should also market to people. Marketing of the site should engage people to want to be part of the process because it is so good. The content of the site should showcase the practical side. Whoever is using a particular standard should be established as a model for how to use that data. The site should speak to public health and get input from public health. People can ask questions and can connect to people who have already done that. These functions should use people's time efficiently, be interactive enough to help people solve problems and not have people leave the site frustrated. An evaluative component of the site will allow people to respond to what they found as well as what they didn't find. Although audio functions may be useful, the site should also allow such materials to be printed for later study or to present to others. In terms of the target audiences, all five levels seem to be important.

Tim agrees that all levels are important, but feels we should prioritize the users. There is one very small group that is attending the standards meetings, but the next group of people that are in the trenches applying these standards is the first priority group to target. These may not be just users of data, but may be the formulators of standards. These may be responsible for large systems that depend on these data, the HIPAA officer, the director of administrative services, the CIO, but perhaps not the top-level director.

Tom believes that the first target audience should be the centers of excellence in public health informatics. Our web site should recognize these centers and they should know our perspective. If we focus on these centers and these key people, they will enable us to set things in motion and may pull the data content. This sort of top down philosophy differs from our usual stance of focusing on the basic user, but we don't want to miss those who get things done.

Bob's perspective differed slightly. He indicated that the National Science Foundation is now funding informatics in public health. One question on the grant applications is "How will you meet HIPAA privacy standards?" In order to respond to this question, they need someplace to go so they can understand the implications of the question. They could site this website in their proposal. Local health department people have a computer, but they use paper because they cannot use the tools available on the computer. If the various forms of data could be integrated, there would be more continuity to the work because others could pick up where one person left off. While prioritizing is good, it is hard to identify the priorities. The decision maker comes from a global public health perspective, while the user will be looking for better ways to do their job. They need to have a context for what public health data are and how they can be used before they will be able to use them. Consortium members can play a role to communicate with them to add value and see this as an important place to get information. If each member of the Consortium put one idea tied into this website, it would build constituency and cross-fertilization. Members would also be a good source of where to link to find particular information. The entire membership of the Consortium should decide how to prioritize the target audience for the site.

Discussion of the current work order

Alan discussed the functionality available with this current work order. The work order establishes the basic site. The URL has been obtained already. The basic material will be the web pages with content and organization. The contract will add text and graphics. Even though most members participating in the earlier survey indicated the capabilities of high-speed connections, the plan is to keep the graphics low enough to enable the most access. Text will largely be in HTML, but the site will allow more elaborate formatting like PDF. Other types of files will also be posted, such as Word and Power Point. The site needs to comply with accessibility regulations. The site will also allow e-mail links so that users can send comments. The search engine – Webinator – will permit searches within the site and will allow the WRC to specify a list of sites that the user can also search. Rather than a large number of hits, the user will have hits to sites that are known to be valuable. The web design will enable list serves with special topics. Messages will be archived to become a resource for future searches. The list serves will link e-mails to all members of the listserve. The listserve could also be moderated by a volunteer who might categorize the e-mail activity or screen e-mails for appropriateness. The web design calls for elaborate reporting on who uses the site and what they access. It is also essential to have the capability to join the Consortium or submit dues. Perhaps the site will link to the NCHS site for this functionality. The ability to have an audio tutorial or streaming media will probably not be part of this first generation, or the scope of this contract. These ideas, however, are being captured by Lewin as part of the wish list for the next phase. The plan is to build a site with good architecture to work with a phased approach. The products used to design the web site will allow for growth, evolution and change. Streaming media will eventually be part of this as we are looking forward while creating the first part. The value added to this site is the expert judgment that selects the authoritative and useful sites, not just a global search. If we put it out, it should be good and useful information. For the very inexperienced user, the site might contain a basic tutorial on how to navigate a web site.

The six products outlined in the proposal were discussed. The orientation to the Consortium is a product that can achieve the education and the marketing. It may be used as a tool kit. People can download a presentation about the Consortium to use in their own organization. Likewise, the reporting guide can be

used as a standard format for reporting data. This targets the collectors and users with products more than Power Point.

The Public Health data use tutorial will focus on the structure of public health state and local levels of staff, function, and how data flows through. The first generation may be static text based, but could ultimately be audio or more elaborate. The tutorial will show the user what a standard is and why it is necessary. Data frequently shows up on people's desktop, rather than computerized because it doesn't merge. There is no definition of the data elements. The tutorial would focus on the idea of standards to demonstrate how epidemiology and vital statistics can match data elements so that issues can be tracked. Perhaps vignettes could be used to develop a detailed discussion of the business case for the context of standards. Bob suggested that all members view the CDC video entitled, "Public Health Data – Our Silent Partner." Tom will send out a link to access the video. Members should look at the video and decide what is missing.

It was also suggested that the web site might contain a questionnaire that would allow users to determine if they need the tutorial or not. Sort of, "if you can answer these questions, then move forward. If not, then do the tutorial." If the site is too basic, then people will shut down, so people need to know where to start. The site could also be role based or skill level based which may give people an idea of where to start. We do have roles defined in our survey, so that may help. Perhaps it could be visually like the malls that post a "you are here" sign. Another possibility is to describe what you have and let the user pick where to go. It will be necessary to have a certain degree of redundancy so people can get information on several different paths. The tutorial should be general, but it should provide links to other levels of information or other types of tutorials, such as the Johns Hopkins site. The information should also provide a calming insight. Sometimes people think that data standards don't apply, such as with HIPAA, and then they become afraid of it rather than seeing how it can be useful. Lewin will be outlining the first three products within a month. Workgroup members should review these to see how the products fit together and integrate.

Products 4,5,6 are not being developed by the contractor but Lewin is editing the products of other workgroups. These products will demonstrate how administrative and clinical functions come together. Members who have comments on these products should post them to the listserve.

Discuss the type of resources accessible by Lewin

The task order outlines initial thoughts on how to talk to folks engaged in similar activities. Three or four websites seem to stand out as exceptional and we should profit from the lessons learned from these best web sites. The initial list contains the WEDI-SNIP site and the MHCCM. Lewin will plan to talk to the creators of these sites. We want to be the WEDI-SNIP site for public health. Additional sites to explore: 1) CDC is setting up an intranet for standards – Steve Steindel? 2) regional training centers for CMS. Hopkins is the training center for their region – Bob will send names of those creating that site.

Christina expressed gratitude for the input on this call and is looking forward to the monthly calls. Suzie inquired as to the feasibility of the suggested dates for workgroup calls. The time 1:30 to 2:30 ET was suggested and members should get back to Suzie regarding those times. Alan will contact Tom regarding PHDSC information.

Action Items

- WG members to think of one idea they would like to see presented on the web site. All Steering Committee members will be asked for this as well.
- WG members to suggest web sites they would suggest the WRC link to
- All Steering Committee members to be consulted about their thoughts about prioritizing the target audience.
- Tom to send a link to the CDC video, "Public Health Data, Our Silent Partner"
- WG members to view the video and suggest missing elements
- Lewin to outline the first three products from the task order within a month

- WG members to review these outlines and make suggestions on integration
- WG members to submit suggestions regarding the other three products from the task order.
- Bob to send names of creators of the Hopkins website.
- WG members to respond to Suzie regarding the proposed schedule of conference calls and times.
- Alan to contact Tom regarding PHDSC information.